Evaluation of a patient satisfaction survey following screening for HIV related neurocognitive impairment

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Background

• Prevalence of HIV related neurocognitive impairment (NCI) is felt to be increasing in the post ART era

• Profile of neurocognitive impairment is changing

• Screening for NCI is controversial
  – Little evidence
  – No perfect screening tool
  – Possible increase in anxiety in asymptomatic patients
  – No clear treatment for HIV related NCI due to concern over anxiety/distress caused by a positive diagnosis

NCI Screening Clinic

• Chelsea and Westminster have established a pan Directorate NCI screening clinic

• Screening involves:
  – Depression/anxiety questionnaire (GAD-7; PHQ9)
  – Everyday Memory questionnaire (EMQ)
  – International HIV Dementia Score (IHDS)
  – Brief Neurocognitive Score (3 written tests)
Service Evaluation

Aim
• To evaluate patient satisfaction with the screening service at Chelsea and Westminster

Method
• An 8 point questionnaire developed in collaboration with the Department of Psychological Medicine
• Questionnaires administered to 101 consecutive HIV positive patients screened either as part of NHS service or as part of cohort study
• Questionnaires completed anonymously and deposited in a designated post box

NEUROCOGNITIVE SCREEN SURVEY

We are asking people who have recently had a neurocognitive screening assessment (where you completed memory tests, puzzles and mood questionnaires) for their feedback. This information will help us evaluate the clinic and make us aware of any changes or improvements we could make. It is up to you if you would like to complete this questionnaire or not. It is completely anonymous, and will not affect your medical care in any way. When you have finished, please return it in the envelope provided.

1. Whose idea was it to have your memory tested? (please circle all that apply)

<table>
<thead>
<tr>
<th>Mine</th>
<th>Friend/Family</th>
<th>HIV Doctor</th>
<th>HIV Nurse</th>
<th>Health Advisor</th>
<th>GP</th>
<th>Psychologist</th>
<th>Other…...</th>
<th>Not sure/Don’t know</th>
</tr>
</thead>
</table>

2. Before you had the assessment did you understand the reasons for it and what would happen?

Yes  No  Don’t know

3. How helpful did you find the neurocognitive screening assessment?

<table>
<thead>
<tr>
<th>Not at all helpful</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Extremely helpful</th>
</tr>
</thead>
</table>
4. What did you find most helpful about the assessment?

5. What did you find least helpful about the assessment?

6. Did the results worry you or make you feel better about your memory?

<table>
<thead>
<tr>
<th>Worried me</th>
<th>Made no difference</th>
<th>Felt better</th>
<th>I didn’t understand / know the results</th>
</tr>
</thead>
</table>

7. What was the plan after your assessment? (please circle all that apply)

<table>
<thead>
<tr>
<th>Nothing needed</th>
<th>More memory testing</th>
<th>Do the screen again later</th>
<th>Brain scan (MRI)</th>
<th>See a psychiatrist</th>
<th>See a psychologist</th>
<th>Other . . . . . . .</th>
<th>Don’t know</th>
</tr>
</thead>
</table>

8. Do you have any other comments or feedback?

Thank you for completing our questionnaire. Please return it in the envelope provided.

### Results

- **Qu 1.** “Whose idea was it to have your memory tested? (n=100)

<table>
<thead>
<tr>
<th>Mine</th>
<th>Friend/Family</th>
<th>HIV Doctor</th>
<th>HIV Nurse</th>
<th>Health Advisor</th>
<th>GP</th>
<th>Psychologist</th>
<th>Other . . .</th>
<th>Not sure/ . . .</th>
<th>Don’t know</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>6</td>
<td>19</td>
<td>64</td>
<td>6</td>
<td>3</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

- **Mine:** 64
- **HIV doctor:** 19
- **HIV nurse:** 6
- **Other:** 3
- **Not sure:** 3
- **Don’t know:** 6
Results

- **Q2.** “Before you had the assessment did you understand the reason for it and what would happen?” (n=98)

  - Yes: 90
  - No: 6
  - Don’t know: 2

- **Q3.** “How helpful did you find the neurocognitive screening assessment?” (n=98)

  - Mean score 7.53

  - Q6. Did the results worry you or make you feel better about your memory?

    - N=4 Made no difference
Results

• Q4 &5. “What did you find most/least helpful about the assessment?” (n=55)

Strongest emerging theme of **reassurance**

Positive comments (n= 47)

- knowing I’m normal
- reassuring that I’m ok!
- reduce my anxiety

Negative comments (n=8)

- Feeling I can’t do it perfectly
- The time it took
- The last test

Results

• Q6. “Did the results worry you or make you feel better about your memory?” (n=99)
Results

Qu 7. What was the plan after your assessment? (n= 87)

<table>
<thead>
<tr>
<th>Plan</th>
<th>(n=87)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nothing needed</td>
<td></td>
</tr>
<tr>
<td>More memory testing</td>
<td></td>
</tr>
<tr>
<td>Do the scan again later</td>
<td></td>
</tr>
<tr>
<td>Brain scan (MRI)</td>
<td></td>
</tr>
<tr>
<td>See a psychiatrist</td>
<td></td>
</tr>
<tr>
<td>See a psychologist</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
</tr>
</tbody>
</table>

Mean satisfaction score 0-10

<table>
<thead>
<tr>
<th>Plan</th>
<th>Mean satisfaction score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred for further investigation (n=31)</td>
<td>7.54</td>
</tr>
<tr>
<td>No further investigations needed (n=46)</td>
<td>7.09</td>
</tr>
</tbody>
</table>

No statistical difference in satisfaction between two groups (p=0.46)

Results

Qu 7. What was the plan after your assessment? (n= 87)

<table>
<thead>
<tr>
<th>Plan</th>
<th>Worried me</th>
<th>Felt better</th>
<th>Made no difference</th>
<th>I didn’t understand/ know the result</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred for further investigations (n=31)</td>
<td>3% (n=1)</td>
<td>52%</td>
<td>42%</td>
<td>3% (n=1)</td>
</tr>
<tr>
<td>No further investigations needed (n=46)</td>
<td>4% (n=2)</td>
<td>50%</td>
<td>46%</td>
<td>0%</td>
</tr>
</tbody>
</table>

No correlation between patient concern and screening outcome
Conclusion

- Majority not worried by neurocognitive screening
- Satisfaction is high following screening for neurocognitive impairment
- No difference in experience between those referred for further investigations and those not
- Limitations of survey
  - Limited demographics
  - Anonymous survey
- Further research and analysis is needed
  - Broader sample group
  - Better qualitative analyses

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